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**AN EVALUATION OF EXPECTATIONS
AND EXPERIENCES OF WOMEN HAVING
ROUTINE ULTRASOUND EXAMINATION FOR
FETAL ABNORMALITIES IN THE MIDTRIMESTER
OF PREGNANCY**

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DECLARATION

I, Malika Patel, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicates otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university. I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

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AN EVALUATION OF THE EXPECTATIONS AND EXPERIENCES OF WOMEN HAVING THE ROUTINE ULTRASOUND EXAMINATION FOR FETAL ABNORMALITIES IN THE MIDTRIMESTER OF PREGNANCY

Introduction: Most studies concerning womens' expectations, knowledge and experiences of the routine ultrasound examination have been conducted in developed countries. We wished to examine the views of women presenting to our service.

Methods: Women who presented for fetal anomaly scans were recruited from the ultrasound departments within the Peninsula Maternal and Neonatal Services. A questionnaire was administered before the ultrasound scan and immediately on completion of this examination.

Results: Two hundred and eleven women were recruited, of whom 206 were interviewed, three declined participation and two withdrew after an adverse diagnosis was made. The most frequently expressed expectation of the ultrasound scan was to determine the sex of the baby($n=99$). This was followed by wanting to know that the baby was healthy($n=80$), establishing the gestational age($n=24$), wanting the scan to exclude any problems with the pregnancy($n=15$) and confirming viability($n=17$). Twenty seven women said they had no particular expectation. The overall background knowledge was very good and there were no differences in knowledge between primigravida and multigravida. Most women received information from healthcare workers at the clinic from where they were referred. Most women had their expectations met and 83% of women had no complaints or bad experiences of the procedure. Concerns included the cold gel, not seeing the baby properly, not receiving a

picture of the baby and one woman felt that her questions were not answered. No one felt threatened by the dark room. Of the respondents, 45% thought the best part of the examination was seeing the baby and 20% felt happy about seeing the heartbeat. Even though half the women wanted to know the sex of the baby, 11% documented that this was the best outcome. After the scan, the feelings expressed were happiness ($n=170$) followed by excitement ($n=96$) and a sense that the pregnancy was “real” ($n=61$) and to some the pregnancy felt real after having seen the baby on the screen. Some women ($n=48$) still documented concern after the scan. The main concern was about the health of the baby ($n=32$), followed by concern for their own health ($n=7$) and one woman felt that the scan may be dangerous to the baby. Of 12 women who had abnormal scans in a previous pregnancy, 10 had no concerns about the baby’s health while 2 said that despite reassurance they remained anxious about the baby. There was no significant difference between women who had scans in other pregnancies or who had experienced early pregnancy complications previously and those who had not.

The difference between concern about the baby’s health before and after the scan was statistically significant ($p=0.0035$). The scan had adequately reassured women about the health of their baby. Most women were reassured about their own health but 13 women who had no concerns before the scan were very anxious afterwards. All the women who had concerns about the safety had no concerns about harmful effects of ultrasound after the procedure.

Conclusion: Most participants in our study had their expectations met by the ultrasound scan and were reassured after the scan. This was a positive event for the majority of women interviewed.

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INTRODUCTION

Diagnostic ultrasound has played an important role in antenatal care since the 1970's as a non-invasive method of prenatal evaluation¹ and has become an integral part of antenatal care in countries with developed health services.² Routine ultrasound scanning is defined as a screening procedure performed on low risk individuals, i.e. pregnant women without a clinical indication for an ultrasound scan.

A Cochrane Review of ultrasound for fetal assessment in early pregnancy³ concluded that there is justification for the use of routine ultrasound examinations in pregnant women. This justification is based on the assumption that ultrasound in early pregnancy allows:

- Better gestational age assessment
- Earlier detection of multiple pregnancies
- Detection of unsuspected fetal anomalies⁴

The value of detecting fetal abnormalities at this stage is to offer couples the choice of termination of pregnancy if a serious abnormality is detected. It also allows those couples who choose to continue the pregnancy to prepare themselves through discussion with healthcare professionals and selfhelp groups while attendants can offer appropriate care during the antenatal period and after pregnancy.⁵ The National Institute of Clinical Excellence guideline on antenatal

care in the United Kingdom (UK) recommends that all women should be offered an 18-20 week fetal anomaly scan.⁴ The best time for these scans is 20-22 weeks as scanning prior to this results in more requests for repeat scans¹. The reasons cited for these repeat requests include inadequate visualization of fetal anatomy (particularly fetal cardiovascular anatomy), early low lying placenta and notching in uterine artery Doppler flow velocity waveforms.

Ultrasound provides early visual confirmation of pregnancy. It is the first contact that the woman has with her baby and also provides some reassurance about fetal wellbeing. Most women react positively to an ultrasound scan because:

- they “meet” the baby, often with other members of the family
- there is visual confirmation of the pregnancy
- they are gaining reassurance about the wellbeing of the fetus⁶

Many women felt more attached to their baby, e.g. “I feel closer to the baby”. “I fell in love with my baby when I saw it.”⁷ A study from Canada, also found that fathers felt more attached to the baby if they attended the scan.⁸ A systematic review found only a few articles which included research on the partners’ experiences.⁶ It has been suggested that for men early pregnancy is the most stressful period, with important changes in the transition to parenthood⁹, and it has been shown that there is a change in attitude of parents regarding their fetus after undergoing the ultrasound examination¹⁰. Most studies show a deficit in women’s knowledge of the purpose for requesting an ultrasound

examination.^{2,6,11,12,13,14,15} In contrast, a study from Denmark showed that there was good background knowledge of ultrasound examinations that was supplemented by family and friends.⁷ However, they concluded that it was possible to increase the knowledge by improved information and access to the information.

Women may put up barriers to obtaining detailed information about the ultrasound scan because of the strong attraction to the idea of having an ultrasound scan,² i.e. “entertainment” ultrasound.¹⁶ There is a belief that offering a service that is routine implies that it is safe and worthwhile. At presentation for ultrasound, a woman may not know the intended purpose and the limitations of the scan. This may leave her vulnerable to shock if an abnormality is detected because she may not have been aware that abnormalities were being looked for. Alternatively, lack of information may also give her a false sense of security. She may, for example, not be aware that all anomalies or neurological deficits are not being picked up at the scan and that the scan essentially serves the purpose of detecting structural abnormalities.

In a study from Sweden, one third of patients could not recall being told that the scan could detect fetal abnormalities, 62% thought the scan was compulsory while 95% of patients were satisfied with information during and after the scan.¹² Another Swedish study, showed that, despite information given before the ultrasound scan was done to indicate that the scan was primarily for dating and

detection of multiple gestation, 89% of women and 84% of male partners thought that the main purpose was for detection of fetal anomalies. In contrast only 13% of women and 17% of men thought it was to reveal the sex of the baby.¹⁴

In another study, ¹⁵ expectations were examined in relation to the following outcomes in primigravidas and multigravidas:

- obtaining a clear photo
- being less worried about fetal health
- confirmation of fetal health and
- being more or less attached to the baby after the scan

There were no significant differences between groups assessed before the examination and over 80% of each group expected the scan to increase attachment to the baby, confirm fetal health and reduce their worry about fetal well being. Early studies showed women were worried that ultrasound would harm the baby but this was not the case in later studies.^{2,7}

Several studies reviewed the different manner in which the scan was conducted. One group would see the screen while explanations were offered (i.e. high feedback) while the other was told at the end of the exam that all was well without actually seeing the screen. It was found that women in the first group were more likely to use positive adjectives like pleasant, wonderful and meaningful.^{6,7,11} It would appear that watching the fetus on the screen is a

positive and reassuring experience. This was also highlighted by a study conducted in Botswana that showed lack of communication of the operator was a major source of client dissatisfaction.¹⁷ This may, however, have been due to language barriers and lack of personnel but is nevertheless an important observation.

Worries about ultrasound scanning included fears of harm to the baby³ and concerns about what the scan might show. Enjoyable aspects included seeing the baby, seeing movement, the reassurance afforded by the scan and the fact that the pregnancy had become more real to the women concerned.¹¹

Pregnancy is associated with increased stress and anxiety.^{2,7} The antenatal scan has been shown to have psychological sequelae,^{1,18} from providing reassurance about fetal wellbeing to shattering hopes of a normal pregnancy. It is therefore reasonable to assume that this intervention, which aims to exclude fetal anomalies, may affect maternal anxiety.

Scans that fail to obtain the necessary information may increase anxiety. This is because women may think that there is an abnormality with the fetus which has caused the scan to fail, e.g. "They could not see the spine. It was not fully developed. We had to go back in two weeks to be checked. I was quite worried. It would have been shattering without my husband."⁷ Some are unhappy about

the way in which the scan was performed, some get bad news and then regret having had the scan and a small proportion choose not to be scanned at all.⁷

The reports on reduction in anxiety after ultrasound scan may reflect increased anxiety prior to the scan and not actually a real benefit of the scan.³ Women may not understand the purpose of the request for ultrasound scan unless they are specifically told about it. However, reassurance from the scan may be transitory. Anxiety was shown to be alleviated immediately post scan but, at interviews conducted 1 week after the ultrasound was performed, mothers highlighted concerns regarding things they perceived as wrong, which may not necessarily have been pathological, e.g. small limbs seen on the screen.

A randomized controlled trial using questionnaires, including the state-trait anxiety inventory instrument¹⁹ to measure womens worries about the health of their fetus before and after the ultrasound examination, either a nuchal translucency scan or a second trimester scan was done. It was found that there was significantly lower rate of worry after the ultrasound, in gestational week 24 compared to before ultrasound in week 10.²⁰

Ultrasound screening during pregnancy has become a well established routine in most countries in the western world² and recent data from Syria and Botswana¹⁷ indicate that it is becoming of global interest. However, these studies have shown that special problems may occur which include an unrealistic belief in technology and doctors' profit interests when ultrasound is introduced in a

population. In the developed world, not all countries offer termination of pregnancy and therefore, the assumption that routine ultrasound can assist in reducing perinatal mortality rates and improve neonatal outcome may not be valid.²¹

The only study identified from a developing country was done by Siegfried Tautz and colleagues.¹⁷ The study was conducted at a district hospital in Botswana and was a qualitative study assessing rural women's experience of fetal ultrasound. They showed that the setting, procedure and communication with patients impacted upon how they felt about the procedure.

Perceived benefits of the ultrasound included getting an accurate gestational age so as to "plan ahead", "How do you know what to fill into your maternity leave forms?" and "Without exact dates no planning is possible".

Three quarters of patients in the Botswana study saw no risk or disadvantage to the scanning process and thought it was beneficial saying that they could face the pregnancy and make plans for it. Some women showed an overestimation of the diagnostic power of the ultrasound scan and the prenatal diagnosis as evidenced by a statement by a woman who had an early intra-uterine fetal death and thought the scan would detect what was "wrong with her womb and whether it is dirty from all the disease we get from our men."

Women in the Botswana study also relied on the information given by the scan rather than on their own bodily functions. Women were reassured by seeing the fetus even though they were at advanced gestation and could feel fetal movements.

Cultural and religious implications also came to the fore in this study. Some women felt that it was against Gods will to see into the womb and they themselves did not want to look at the image. The cold gel was also seen as a magical entity that allowed sight into the womb.

Anxiety-provoking events in developed countries were mainly regarding fetal well being. In developing countries it seemed to be the fear of the unknown technology, i.e. the big machine. Also, women were anxious about many aspects of the study setting, from it being conducted in a dark room to the cold jelly being rubbed onto the abdomen. Most studies investigating anxiety come from developed countries, i.e. Europe, U.K. and USA.

Fetal anomaly scanning has been part of the routine antenatal practice within our clinical service for about 8 years. Annually, nearly 10000 women book for antenatal care before 22 weeks of gestation in the Peninsula Maternal and Neonatal Service. Currently about 5000 of these women have routine ultrasound

scans. Patients in this drainage area are mainly either of black or coloured ethnic origin.

Van Gelderen et al, in a review of ultrasound, ethics and the law stated that: “research is required to assess the expectations of pregnant women in regions such as our own (South Africa), and whether they are satisfied with what they receive.”¹⁶ Bricker, Garcia, et al, in a systematic review of the clinical effectiveness, cost-effectiveness and women’s views of ultrasound screening in pregnancy, recommended “Comparative research on ways in which pregnancy ultrasound is carried out and experienced in different countries and cultures would be valuable.”⁶

This study will attempt to clarify the expectations women have prior to the routine midtrimester ultrasound examination in our clinical environment. The study will then evaluate women’s experiences after the scan. This will give service providers information about how best to prepare women for this important part of clinical practice. This may include informed consent and education and counselling of and by health care workers. The evaluation following the scan may also indicate a need for debriefing or post test counselling. The post test assessments may inform healthcare professionals of how patients experience the ultrasound scan examination and whether we can enhance this experience for the women.

STUDY AIM AND OBJECTIVES

Aim: To evaluate the expectations and experiences of women having routine ultrasound examination to exclude fetal abnormalities at 20-24 weeks of pregnancy

Objectives:

1. To evaluate women's expectations prior to routine fetal anomaly ultrasound scan.
2. To document women's experiences after routine fetal anomaly ultrasound scan.
3. To assess the prevalence of concerns experienced by women having routine ultrasound examination in pregnancy

STUDY DESIGN

This was a prospective cross-sectional study. The study population consisted of women presenting for routine ultrasound screening at between 20 and 24 weeks of pregnancy. The sample was derived as follows:

Inclusion criteria:

- Any woman with a pregnancy at low risk of fetal anomalies having ultrasound examination at 20-24 weeks gestation

The following were exclusion criteria:

- Women with a known or suspected fetal abnormality
- Ultrasound requested because of a known or suspected clinical problem

The questionnaire was piloted on 10 patients at one of the sites and minor adjustments were made to improve clarity where necessary.

METHODOLOGY

The study was conducted at the obstetric ultrasound departments of Groote Schuur Hospital(GSH), Mowbray Maternity Hospital(MMH) and New Somerset Hospital(NSH). The study was conducted under the auspices of the Departmental Research Committee of the Department of Obstetrics and Gynaecology of the University of Cape Town.

The ultrasound unit at GSH is staffed by consultants, medical officers and ultrasonographers. There are 1200 fetal anomaly scans done annually at this unit. The unit at MMH does up to 170 fetal anomaly scans a month and is staffed by ultrasonographers. The unit at NSH was staffed by 1 ultrasonographer who did 70 fetal anomaly scans a month. The monthly delivery rates are 500 births at GSH, 800 births at MMH and 500 births at NSH. The perinatal mortality rate for the area previously known as Peninsula maternal and neonatal services is 42/1000 births.

Two hundred and eleven women were recruited from July 2007 to September 2007. The 2nd trimester scan is part of the antenatal screening programme for those who book early enough to qualify for it. The main benefits of the scan are to determine gestational age, diagnose multiple pregnancy and for detection of fetal anomalies.

Two hundred and eleven consecutive women were approached to participate in the study. Three women declined entry into the study. Two were excluded because the ultrasound showed an intrauterine fetal death. In both cases the women were too distraught to continue. Both were referred to the medical personnel immediately for counselling and further management.

Any woman with a low-risk pregnancy having ultrasound examination at 20-24 weeks of gestation was included. Women with a known or suspected fetal abnormality or women who had an ultrasound requested because of a known or suspected clinical problem were excluded. None of the women had a diagnosis or suspected diagnosis of twins prior to the scan. Womens' HIV status was not available on the request form for fetal anomaly scan. A minority of women had preceding low risk nuchal translucency scan if they booked early enough.

The study was designed to be observational ie. to document the attitudes of a group of low risk women and not meant to be comparative. Therefore it was not subdivided into 2 separate arms with regard to racial groups and previous exposure to scans.

Women were recruited from the waiting area of the ultrasound unit. They were given both verbal and written information regarding the nature and purpose of the study. The study was conducted in English and Afrikaans and via an interpreter for Xhosa and French speaking women. If the women agreed to participate in the study they were asked to sign a consent form. This form reinforced that participation was voluntary, that all information was confidential, withdrawal from

the study would not influence future management and that they could withdraw at any point in the study. All patients gave informed consent prior to enrollment in the study. The consent forms are attached as appendix 1.

The questionnaires were administered while the women were waiting their turn and again immediately on completion of the scan so it did not necessitate any extra time sacrifice by the women who had agreed to participate. Women were allowed to ask any questions regarding the study prior to consent being taken.

Women were asked to complete an administered questionnaire immediately before and after the ultrasound scan. The pre-scan questionnaire was administered by the principal investigator or an assistant. This interview took place in private designated consulting areas at the respective units. The questionnaires were administered individually and completed by one of the investigators. The patient then had the routine ultrasound scan. This scan was performed by a radiographer or medical officer. The radiographer or medical officer did not change their routine for performing the scan or the manner of giving the patient any information at the consultation. The radiographers and medical officers performing the scan were aware that the study was being conducted.

Immediately following the scan, the patient was interviewed again and the post scan questionnaire completed. This interview took place in the same private designated consulting area as the pre test questionnaire. The questionnaires

were administered individually and completed by one of the investigators. Both the pre-scan and post-scan questionnaires were administered by the same investigator. No prompting was allowed and patients were given a few seconds to answer before the next question was asked.

The pre-ultrasound questionnaire sought information on demographic details, previous pregnancies and their outcomes, what information was received regarding the scanning process and what they expected the scan to show them. Women were also asked to comment on specific concerns they had about the scanning process.

The same women had an administered questionnaire immediately after the scan. They were asked about the interaction between the ultrasonographer and themselves. They were asked whether the information they received by the healthcare professionals was adequate and how it could be changed so as to achieve this. Specific questions were asked to ascertain what the best and the worst part of the scan was. Direct closed questions were asked once the open ended question was asked.

The pre-scan interview lasted 15 minutes and the post-scan interview lasted 10 minutes. No management decisions were made. The patients were then referred back to their local clinic or doctor in charge to interpret the ultrasound scan report and continue appropriate management. The questionnaires are attached as Appendices 2 and 3.

ETHICS

Consent for the study was granted by the Human Research Ethics Committee of the University of Cape Town. The UCT Ethics Committee consent is attached as Appendix 4. Permission was also granted by the Medical Superintendents of the 3 hospitals concerned.

DATA

Data were of both a qualitative and quantitative nature. Some questions were open ended while others had given answers where the woman had to choose the appropriate answer. Variables were tabulated in a Microsoft Excel® spreadsheet. The database was checked and verified by the principal investigator. The data set was complete. The spreadsheet is attached as Appendix 5.

STATISTICAL ANALYSIS

Statistical assistance and advice was provided by Dr Landon Myer of the Department of Public Health and Family Medicine of the Faculty of Health Sciences of the University of Cape Town. Statistical analysis was performed by Stata™ Edition 10, Special Edition. Concerns regarding the health of the baby were compared before and after the ultrasound scan examination. It was analysed using paired t test. P values <0.05 was considered significant

Descriptive data were tabulated and analysed for differences between baseline characteristics. The analysis of before and after data was performed by calculating paired t-tests. Comparisons of before and after levels of concern were analysed using chi-square tests.

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RESULTS

There were a total of two hundred and eleven women who were invited to participate in the study. Three women declined and two received adverse diagnoses and were too distraught to continue. Therefore, a total of 206 women were included in the final analysis of the study. A total of 53 women were recruited from Groote Schuur Hospital, 90 women recruited from Mowbray Maternity Hospital and 63 women from New Somerset Hospital. There were no significant differences between the demographic profiles of the patients recruited from the various units. The demographic details are presented in Table 1.

The distribution is in keeping with the ethnicity of the patients that access the public hospital services in Cape Town. The majority of the women were from black and coloured race groups with 61% of women from the coloured race group and 38% from the black race group. Only 1 white woman was interviewed during the study.

Table 1 – Demographic details of patients having ultrasound examination

AGE	Median=26 Min=16 Max=40
SITE GSH MMH NSH	N=206 53 90 63
RACE Black Coloured White	N=206 78 127 1
RELATIONSHIP Single Married Living with partner Other	N=206 71 99 21 15
EDUCATION No formal education 1-7 years 8-11 years Matric or further studies	N=206 1 10 82 113
GRAVIDITY Primigravidas Multigravidas	N=206 87 119
PREVIOUS PREGNANCY OUTCOME Miscarriage/ectopic Stillbirth/NND 1 or more live children	37 14 103
ACCOMPANIED YES NO	N=206 103 103
ACCOMPANIED BY Husband/partner Mother Other	N=103 76 12 15
PREGNANCY PLANNED Wanted Unwanted	N=103 103 0
PREGNANCY UNPLANNED Wanted Unwanted	N=103 99 4

The gestational age was between 20 and 24 weeks and they were all referred for fetal anomaly scanning. The median age was 26 years, with the age range between 16-40 years. Forty two percent were in their first pregnancy, i.e. primigravidae, while the rest had experienced one or more pregnancies, regardless of pregnancy outcome. Of the women who had experienced a previous pregnancy 103 had 1 or more live children while there were 51 had previous adverse pregnancy outcomes, ie a pregnancy complication. One hundred and three (50%) women had planned this pregnancy while 103 women had an unplanned pregnancy. In the unplanned group 99 women still wanted to continue with the pregnancy despite not having planned it. Four of the women within the unplanned pregnancy group no longer wanted the pregnancy. These will be discussed later.

One hundred and twenty women were in a stable relationship. Ninety nine of these women were married, 21 women were living with their partner and 15 women had a boyfriend or partner. Seventy one were not in a relationship at the time of the interview.

Almost all the women had some form of education with 113 women having had 12 years of education or a tertiary degree. Eighty two women had 7-11 years of education while 10 women had less than seven years of education. One woman had received no formal school education.

Half the women in the study were accompanied to the scan. This is despite nearly 70% of women reporting that they knew that they could be accompanied. The vast majority (80%) of women who were accompanied brought their husband or partner along.

Expectations

Unprompted expectations from the scan

An open ended question was posed to the participants asking them what they expected from the scan. There were sometimes just 1 answer, with some women giving up to 3 expectations they had prior to having the scan.

The most frequently expressed expectation from the ultrasound scan was to see the sex of the baby with a total of 99 women wanting to know their baby's gender. A total of 80 women wanted to know that the baby was healthy. 15 women wanted the scan to exclude any problems. 24 women thought they could be told the duration of the pregnancy by undergoing the scan. 17 women wanted to know that their baby was alive. 27 women had no expectation from the scan.

Background knowledge and information

Women were asked specific questions regarding general capabilities of an ultrasound examination. Questions included whether the ultrasonographer could

assess if the baby was alive, whether the baby was normal, if there was a multiple pregnancy, the gestational age of the pregnancy and the sex of the baby. We then looked at the differences in expectations of primigravid women compared to multigravid women. Statistically significant differences are expressed as p-values <0.05.

These results are shown in table 2.

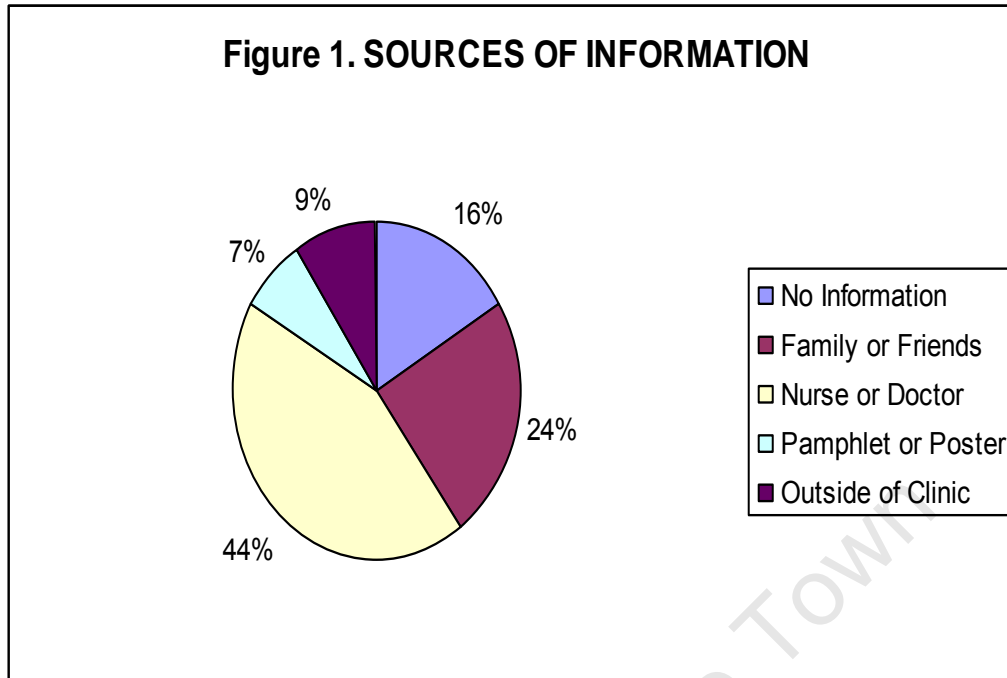
Table 2 – Differences between expectations of primigravid and multigravid patients

EXPECTATION n=206	PRIMIGRAVIDA n=87	MULTIGRAVIDA n=119	ALL PATIENTS n=206	p-values *
Baby alive PROMPTED:Yes No Don't know UNPROMPTED	82 1 4 12	115 0 4 5	197 (96.5%) 1 (0.5%) 4 (3.9%) 17	0.061
Baby normal PROMPTED:Yes No Don't know UNPROMPTED:Yes	78 1 8 27	108 3 7 53	186 (90.7%) 4 (2.0%) 15 (7.3%) 80	0.380
More than 1 baby Yes No Don't know	69 15 3	89 21 9	158 (76.7%) 36 (17.5%) 12	0.449
Gestational age PROMPTED:Yes No Don't know UNPROMPTED:	78 1 8 12	112 0 7 12	190 (92.2%) 1 (0.5%) 15 (7.3%) 24	0.431
Gender PROMPTED:Yes No Don't know UNPROMPTED:	81 3 3 43	114 1 4 56	196 (94.6%) 4 (1.9%) 7 (3.4%) 99	0.607

* none of the p values reached statistical significance

The overall background knowledge of our group of women was very good. Just more than 95% of women thought that one could see that the fetus was viable. 90% thought the scan could reassure them that the baby was normal. Seventysix percent knew that an ultrasound scan could diagnose a multiple pregnancy. Just over 92% knew you could date the pregnancy with the 22 week scan. Nearly 95% of women thought you could assess the gender of the fetus at fetal anomaly scan. We did not ask about specific anomalies as the current practice is not to counsel women on the ability of the scan to pick up specific fetal anomalies.

None of the p values reached statistically significant levels indicating that there were no differences in expectations between primigravidas and multigravid women.



The sources of information obtained by women having a routine ultrasound examination are presented in Figure 1. Most women received information from the nurse or doctor in the clinic from where they are sent for the fetal anomaly scan. This was followed by information from family and friends, with 24% women receiving information from this source. Nine percent of the women received information outside the clinic from sources like books and the internet. Sixteen percent of women received no information at all. Some women gave more than one source of information.

Table 3: Sources of information analysed by gravidity

	No Information	Family & Friends	Dostor or nurse	Posters	Other
Primigravida	19	16	43	2	7
Multigravida	22	17	68	7	5

Pearson $\chi^2 = 4.1201$ p value = 0.390

When comparing the information sourced between primigravidae and multigravidae there were no significant differences between sources of information.

Experiences

Where women's expectations met?

As shown earlier, women presenting for their fetal anomaly scan had specific expectations from the scan. Questions were posed to the women to assess whether these expectations were met during the scan. These results are shown in table 4.

Table 4 – Proportion of expectations that were met during the ultrasound examination

	EXPECTATION	EXPECTATION MET	PROPORTION WHOSE EXPECTATIONS WERE MET
Baby alive	17	15	88%
Baby healthy	80	75	94%
Gestational age	24	21	88%
Gender	99	60	60%

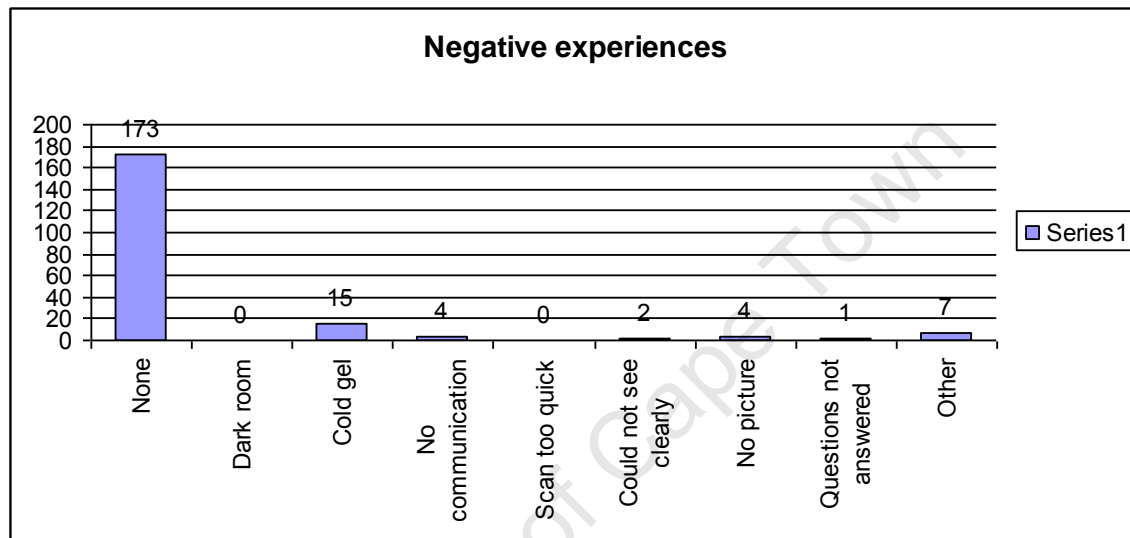
Of the 17 women who expected to see that their baby was alive just under 90% had their expectation met. 1 woman said she was not told or did not see the baby's heartbeat and 1 woman was not sure what she saw. Ninety four percent (75/80) saw or were told their baby was healthy. Just over 6% (5/80) reported that they did not see or were not told that the baby was normal.

Eighty eight percent (21/24) of the women who wanted to know their gestational age were told how far pregnant they were. Three women reported that they were not told their gestational age. Ninety nine women reported that they wanted to know the sex of the baby. Only 60% (60/99) received this information. Thirty three percent of the women in this group (33/99) did not receive this information and 6% (6/99) were unsure of the baby's gender.

Negative experiences of the ultrasound scan procedure

Women were asked what they disliked about the scan. Their answers are shown in figure 2.

Figure 2: Negative experiences of the ultrasound scan procedure

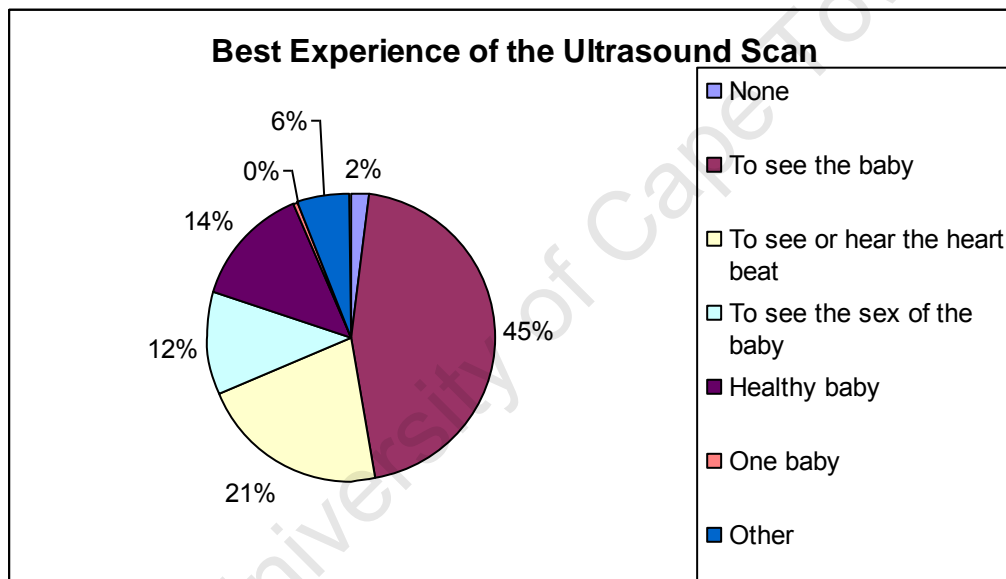


Eighty four percent (173) of women had no complaints or bad experiences of the scan or the scanning process. Just over 7% (15) of the women had some concerns about the cold gel that was put on their abdomen to help visualize the baby. Two (1%) women complained that they could not see the baby properly. Four women (2%) were unhappy about not receiving a picture of the baby. One woman felt that her questions were not answered. No one felt threatened by the dark room. None of the women felt that the process was over too quickly.

Positive aspects of the ultrasound scan procedure

Figure 3 illustrates the distribution of the experiences that stood out as the best part of the scanning process.

Figure 3: Best experience of the ultrasound scan procedure



Just over 45% (93) of women thought the best part of having the ultrasound examination was seeing the baby. Twenty one percent (43) felt happy about seeing the heartbeat of their baby. Five (2.4%) women did not feel that there was any part of the scan that stood out for them as being the most memorable. One woman was happy that there was only 1 baby. Some women felt happy about sharing the experience with their partners.

Feelings regarding the scan

Women had very specific feelings regarding the scan. Some women chose 2 answers and both were recorded. They are summarized in table 5.

Table 5 – Feelings expressed after the ultrasound examination

FEELINGS	YES
None	6 (2,9%)
Happy	170 (82,5%)
Excited	96 (46,6%)
Pregnancy feels real	61 (29,6%)
Concerns:	
Baby's health	26 (12,6%)
Own health	22 (10,7%)

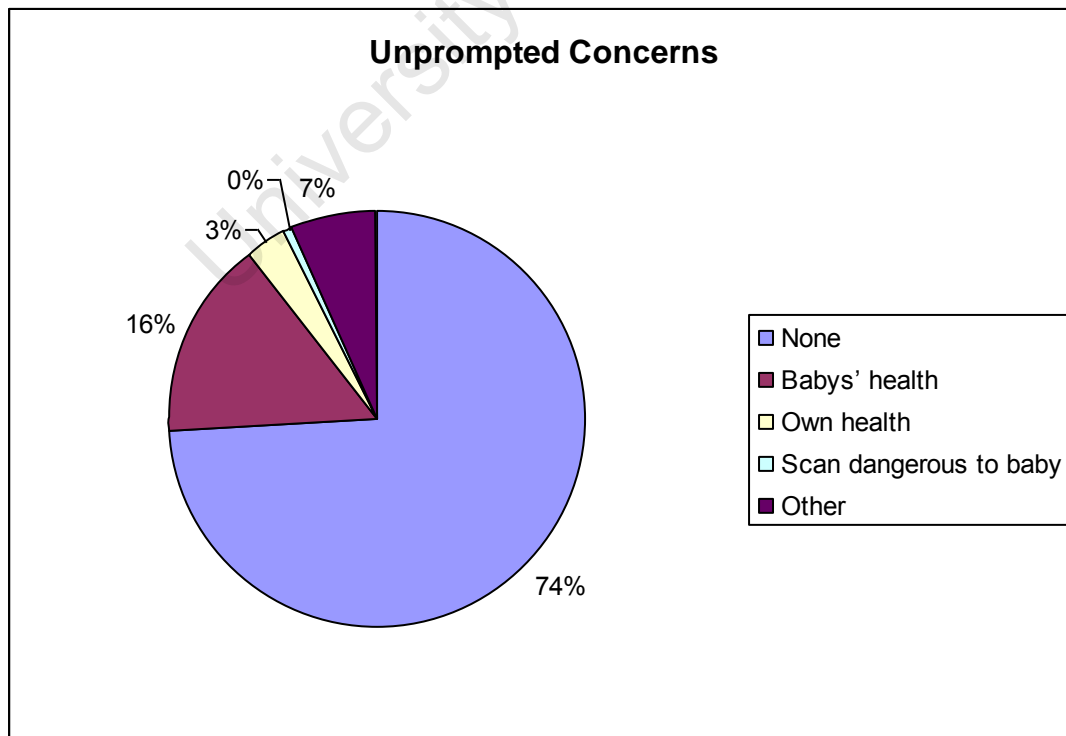
Most women felt happy after the scan. This was followed by excitement and to some the pregnancy felt real after having seen the baby on the screen. There were, however, some women who still experienced some form of concern after the scan. These concerns will be discussed further in the results below.

Of the 4 women that stated that their pregnancies were unplanned and unwanted: All 4 had had previous pregnancies, all had come alone even though they knew they could have been accompanied. They felt indifferent to the scan prior to the examination and had no concerns regarding the scan. However after the scan all 4 women were happy to see the baby and described their feelings as either happy or excited about the pregnancy.

Women's concerns regarding the scan

54 women had some concerns regarding the fetal anomaly scanning process while 152 (nearly 74%) didn't have any concerns. The specific concerns are presented in Figure 4.

Figure 4– Concerns of women before having the scan



The majority of the women who expressed concern about the scan felt that their main concern was about the health of the baby, with 32 women feeling this way. 7 women were concerned about their own health and 1 woman felt that the scan may be dangerous to the baby. .

Table 6 – Womens' concerns analysed according to previous obstetric history

	CONCERNS		
	YES	NO	p-value*
<u>SCANS IN PREVIOUS PREGNANCY</u>			
YES	27	66	0.404
NO	27	86	
<u>MISCARRIAGES</u>			
NO	41	128	0.173
YES	13	24	
<u>PREVIOUS SB/NND</u>			
NO	48	144	0.204
YES	6	8	

*none of the p values reached statistical significance.

Table 6 looks at the concerns in women depending on their previous obstetric history. Statistically significant differences are expressed as p-values < 0.05. There was no significant difference in concerns of women who have had scans in previous pregnancies and those of women who are having a scan for the first time.

Women who experienced a previous early pregnancy complication resulting in miscarriage were compared to women who never had a previous miscarriage.

There was no significant difference between these two groups. This will be explored further in the discussion.

Specific concerns

Table 7 shows the concerns that were specifically asked about. A visual analogue scale was used to assess levels of concern. A scale of 1 to 5 was used where 1 was slight concern and 5 was maximal concern.

Table 7 – Concerns expressed by women having routine pregnancy ultrasound

CONCERNS	YES	NO
Baby's health	54	152
1	1	
2	2	
3	8	
4	8	
5	35	
Own health	52	154
1	7	
2	1	
3	11	
4	5	
5	28	
Scan dangerous to mom	49	157
1	37	
2	3	
3	1	
4	0	
5	8	
Scan dangerous to baby	51	155
1	37	
2	1	
3	1	
4	1	
5	11	

Concern about baby's health

54 women felt concern for their baby's health. 35 of them classified it as extreme concern, marking it as a 5 on the scale of concern. Concern about the baby's health was the commonest concern expressed.

Concern about own health

52 women were concerned about their own health with 28 of them experiencing extreme concern.

Concern regarding safety of scan

49 women expressed concern that the scan posed some danger to them. 37 of them felt only slight concern while 8 felt extremely concerned. 51 women were concerned about how safe the scan was to the baby. The majority (37) were only slightly concerned. However, 11 were extremely concerned for their baby's safety.

Concerns following the scan

132 women who had no concerns about baby's health before the scan had no concerns after the scan as well. However, 18 women who had no concerns before the scan had the maximal concern after the scan. Of the 35 women who had maximal concern before the scan 30 had no concern after the scan and in 5 women the level of concern was not diminished by the scan.

The difference between concern about the baby's health before and after the scan was statistically significant ($p=0.0035$). The paired two-tailed ttest was used.

Table 8. Statistical analysis comparing level of concern about the baby before and after the scan

Variable	Observations	Mean(SD)
Concern before	206	1.146 (1.992)
Concern after	206	0.617 (1.618)
Difference	206	0.529 (2.571)

Paired t-test = 2.954, $p=0.0035$

This shows that the scan has adequately reassured women about the health of their babies'.

Most women were reassured about their own health after they had undergone the scan. However, a small proportion of women who had no concerns about their own health before the scan had maximal concern after the scan, (13 of 154 women, i.e. 8, 4%).

All 49 women who had concerns about the safety of ultrasound to themselves had no concerns after the test was performed. Just fewer than 25% of women were worried about ultrasound being harmful or dangerous to their babies. All these women had no concerns about harmful effects of ultrasound after the procedure.

DISCUSSION

The fetal anomaly scan is carried out between 20 and 24 weeks and aims to assess whether there are anomalies of the major organ systems. The detection rate of these anomalies varies and is dependant on the organ system reviewed and the skill of the operator. Most women appear to want an ultrasound examination and routine ultrasound seems to be popular with high uptakes in international screening programmes.^{12,14,21,22} It has been suggested that this could be because ultrasound is non invasive, leading to the examination having predominantly a social meaning. Some women may see it as an important landmark in the pregnancy.^{14,23,24} Women have differing expectations of the ultrasound scanning process

The majority of the women in this study wanted to know the sex of the baby. This is not a routine part of the fetal anomaly scan. Studies done in the UK, Sweden and Denmark showed that wanting to know the sex of the baby was listed as an expectation but it was not rated in the top 3 reasons for the scan.^{14,23,29} The women in the UK rated reassurance that the baby was alright, checking for fetal abnormalities and checking for chromosomal abnormalities as 3 main purposes for the scan. These women, however, do get information leaflets prior to the appointment for ultrasound scanning.²⁹

The issue of determining the sex of the baby seemed very important for the women despite the fact that they do not always articulate the desire to acquire this information from the ultrasonographer. Women often display a sense of relief when the sex of the baby matches their preferences. Having a male child may be essential in local culture – often as a potential breadwinner²⁵.

A study from Denmark found that women in lower income groups were more likely to want to know the sex of the baby and to want a picture of the baby while women from higher income groups were more likely to want the scan to check that all was normal and for their own reassurance.²⁶ In this study most women had secondary and higher education and we did not record income groups. There are prospective parents who see antenatal ultrasound as a means of learning the sex of the baby and women who are carrying a baby of the “wrong” gender are more depressed and experience more labour problems.^{27,28} In some studies women were upset when the sex of their baby was revealed by the ultrasonographer without it having been requested.² None of the women in our study were upset about having the gender of their baby revealed.

Another expectation expressed in this study was the need to check that the baby was healthy. Conversely, there was a small group of women who interpreted this expectation differently, by saying that they wanted to have the scan to exclude problems with the baby. This may be attributed to some women being health orientated while others are problem orientated. It seems that women assume

fetal health if they are healthy, experience pregnancy symptoms and have been through a pregnancy before³⁰ and therefore seek reassurance from the scan. Ultrasound scanning for fetal anomalies only picks up 50% of significant abnormalities.³¹ A study from Sweden showed this to be the foremost parental concern and many parents think that the scan is a procedure for detection of fetal malformations and a kind of health declaration.¹⁴ Women in our setting do not get formal routine counselling or information leaflets before the scan so they are not aware of the ability of the scan to exclude malformations or abnormalities.

There are women coming to the scan with no expectation at all. Whether this is a product of inadequate counselling of the ultrasound process or whether these women just could not recall what they were told was not examined in this study but there were a number of women who did not receive any information or counselling to understand the purpose of the scan. The majority of women going for the scan were excited or felt good about seeing the baby. Thirteen percent were guarded about the scan.

Surprisingly, there was no difference in expectations and knowledge between primigravidae and multigravidae suggesting that there is no influence of previous pregnancy on background knowledge of the ultrasound scan. This was in keeping with a study done by Lalor in Ireland.¹⁵ In contrast, a study from Denmark showed a definite difference with women in their first pregnancy being more interested in seeing the baby than women who had previous deliveries.

Women who had previous miscarriages also had different reasons than others for wanting a prenatal ultrasound scan ie. wanting to see if there was life and to see the heartbeat.²⁶

Women who have normal pregnancies have specific reasons for wanting prenatal ultrasound and these may be influenced by socio-demographic, obstetric and attitudinal factors²⁶. We did not specifically stratify our women according to income groups. The levels of education of the women were mostly of secondary level or higher, therefore there was some insight into what was happening. Women are aware of the diagnostic potential of ultrasound scanning but it is regarded as a source of reassurance rather than potential source of bad news.²⁴

Most women had preconceived ideas as to why they were having the scan. These reasons were similar to those found in other studies.^{14,23,29} Women were aware of the diagnostic possibilities of the ultrasound scan and that their prompted and unprompted expectations are relevant from a clinical point of view. More than 90% of women in this study knew that an ultrasound scan could tell one that the baby was alive, whether the baby was normal, the gestational age and the gender of the baby. Just fewer than 80% knew that the scan could show a multiple pregnancy. However, 10% of women did not know or were not sure whether a scan could show a normal baby.

The availability of information on procedures, influences the choices made by women on whether or not to undergo the procedure or testing. A lack of information and a lack of understanding may lead to women refusing a prenatal screening procedure. However, more information and understanding may serve to dissuade women from undergoing procedures.³² A recent study showed that informing women fully of all the ultrasound detection rates of the various anomalies may be counterproductive and will result in enhanced worry about the pregnancy.²¹

In this study 16% of women received no information at all. These women, therefore, undergo ultrasound scanning with no knowledge about the process at all. Half the women received information from the health care professional. There are no standardised information sheets or brochures available which suggests that the information provided is subjective and may not be consistent. Family and friends play an important role in propagation of this part of antenatal care. They may be drawing on their own experience of the procedure and once again may not be factual. Public knowledge may be improved through general information like awareness campaigns using the media.²³ It is also becoming easier for parents to access information for themselves via the internet.^{7,30} Eleven percent (11%) of the women had accessed the electronic media and books for information regarding the ultrasound examination. We cannot evaluate the quality of the information as the study was not designed to do this. It is,

however, imperative to check, in future research, the type of information received and whether it is possible to standardize this information.

The experience of the obstetric ultrasound is dependant on several interacting factors. These include the clinical objective for the scan, what women know about the purpose of the scan and likely outcomes.² The setting for the scan and the interaction with the staff and the manner in which the findings are imparted may also influence their experiences.

Women had their expectations met in most cases with 80% of women getting expectations of gestational age, baby's health and learning about viability met. Less than two thirds of women who wanted to know the sex of their baby actually received this information. This is an interesting finding as the expectation that was the most cited was the one that was least met. This is because it is not the purpose of the scan and hence is not actively sought despite women thinking that this was the main purpose for them wanting the scan. Again, this may be a result of inadequate counseling prior to the scan. Also most women wait till the end of the exam and ask the ultrasonographer what the sex of the baby is after the exam is finished.

Women in this study, found the ultrasound examination to be a positive experience, describing it as an exciting and happy experience. This is in keeping with all other studies.^{14,2332,33} To see or hear the heartbeat was an especially

memorable experience. It established life for the women – the pregnancy seemed real now. Therefore seeing the baby reassured women and seeing the baby gives women the knowledge that the pregnancy was a real entity.

The desire to see the baby is so strong that parents cannot resist the opportunity³³. For some women it may be necessary to have the pregnancy confirmed by a professional. The fetus, once seen, becomes a separate entity for which the woman is responsible.^{34,35} It has also been shown that women who see the fetus as the examination progresses and receives an explanation as this is done, are more reassured than women who are just told the fetus is healthy without visualizing the fetus.³⁶ This was expressed by our sample of women as well. Some women expressed that they wanted more scans just to see the baby or movement again. Feminist theorists have argued the dislocation of experiential knowledge ie. Women enjoy and come to rely on a technologically mediated introduction to their pregnancy-the experience of seeing demoted bodily experience to second order significance^{34,37}

Dissatisfaction arose when there was inadequate communication. This most commonly involved failure to reveal or to explain the image. However, more than 80% of women in our study had no dislikes of the process at all.

This good correlation between expectations and experiences along with actually seeing the baby, which nearly half the women described as the best experience,

make the ultrasound experience a positive one. This was followed by hearing or seeing the heart beating. Next, was hearing that the baby was healthy. This was in keeping with most other studies conducted.³² Seeing the sex of the baby was only rated 4th as a positive experience and although nearly half the women wanted to know the sex of the baby only, 13% thought that it was the best experience of the scanning process.

The women in our study were low risk and we did not continue interviewing those with an abnormality picked up due to emotional distress of the patients. We therefore do not know the impact of little, no or inadequate information in these patients- this too is an interesting aspect to look at in future.

Very few women opt out of having a scan because the experience itself is thought to be psychologically rewarding.²⁷ Although women were positive towards the information they received and also positive towards the scan, the understanding of the prenatal information is lacking as they do not know of specific detail on prenatal testing. Taking this into account, it seems as though the choice to have the scan is not well informed.^{32,38}

The study from Botswana examined rural womens' experiences of ultrasound scanning¹⁷. Most of the women viewed the ultrasound as beneficial but there was also a considerable amount of fear associated with the process. The fear included the setting ie. The dark room, the cold gel, seeing the image on the

monitor and the inadequate explanation of the procedure – mostly due to language barriers. Staff were unaware of these fears. While our sample felt that ultrasound was beneficial they did not express the same fears.

No one was afraid of the setting in which the procedure took place. Fifteen women were concerned about the cold gel put onto their abdomen with one woman from the Congo saying that she was worried about the magic gel that enabled one to see inside the tummy. This, however, did not detract from the excitement that accompanied the ultrasound scan experience. All the women felt that the ultrasound process was of adequate length but there were women who were unhappy that they could not get a picture of the baby. This, once again, highlights that the process is seen as a social one. Our sample of women does represent an urbanized population.

Lack of information regarding the purpose of the scan may leave one open to a shock if a problem is encountered at the scan. However, this may also lead the woman to believe that all is well in the absence of detected anomalies.

The ultrasound scan examination has been shown to have psychological sequelae from providing reassurance about fetal well being to shattering hopes of a healthy pregnancy.³⁹ Concerns reviewed in this study were divided into health of the mother and baby and dangers of the ultrasound scanning process to the mother and the baby. Most of the concerns were for the health of the

baby; this was followed by concerns for their own health. Although there was concern regarding the safety of the ultrasound scan this is probably due to inadequate explanation and understanding of the process. In other studies the safety of midtrimester ultrasound was not an issue that women discussed with their medical practitioners. The statement of safety of Grey scale imaging of the Australasian Society for Ultrasound Medicine(1999): “Grey scale imaging by transcutaneous, transvaginal and endoscopic routes is a well established procedure in diagnostic medicine. To date, the results of follow up studies on patients and children who had been examined before birth have not demonstrated a causal link between adverse health effects and ultrasound exposure”.⁴⁰

Thirty two women mentioned concern about the baby as an unprompted concern while the women who had concerns and were prompted regarding the concern for the baby included all 54 who said that they had some concern about the ultrasound scan. Interestingly, of the women who had previous pregnancy complications only 2 expressed concern about the baby's health. The women were reassured by the scan with the majority of women having no concerns for the baby's health after the scan.

There were no significant difference in concerns of women who have had scans in previous pregnancies and those of women who were having a scan for the first time. Intuitively, it may have been expected that women who never had a scan

before should be more concerned about the procedure and with what the scan may show.

When assessed for previous pregnancy complications, women who experienced a previous early pregnancy complication resulting in miscarriage, were compared to women who never had a previous miscarriage. There was no significant difference between these two groups. This may be attributed to the fact that they are past the critical period when their miscarriage occurred. It may also be that they now have felt fetal movements and so the pregnancy may feel established or that they feel “life” and therefore are not concerned. Again, lack of insight may play a role in how the women answered the questions and this could be cleared up by providing adequate information to the women about the purpose and limitations of the scan.

There was no significant difference in concerns of women who experienced a previous late pregnancy loss. A late pregnancy loss being defined as fetal death after the pregnancy has reached viability – in South Africa, a pregnancy that has reached 28 completed weeks – or early neonatal death.

We did not ask specifically where in the obstetric history the fetal or neonatal loss occurred. It may well have anteceded a pregnancy that resulted in a live birth and therefore women's fears and concerns were allayed. The reason for the loss may also have an impact on the concern. If it was unrelated to obstetric causes

and the exact nature was explained to the women she may not have heightened concern. We did not distinguish between fetal death and neonatal death so that specific difference could not be assessed. It may also be that the excitement of the new pregnancy is overwhelming and the women only are concentrating on the joys of seeing or 'meeting' the baby for the first time.

Women often attempt to establish a relationship with the ultrasonographer and it was found in other studies that women polarise their feelings about ultrasound scanning as good or bad based on how well they were able to forge a relationship with the ultrasonographer regardless of it is a radiologist or radiographer.⁴¹ This was demonstrated in this study as well with one woman attributing her heightened concern to not connecting with the ultrasonographer and said she didn't get any feedback at all. Only 4 women felt that there was inadequate communication, with 2 women saying that they could not clearly see the baby. Most women felt that their questions were answered and that there was good communication between them and the ultrasonographer and that they got an adequate explanation.

The provision of adequate feedback has been found, in a systematic review of randomized controlled trials, to be an essential factor in positively experiencing ultrasound scanning.^{3,42} A study from Denmark showed that screening for Down's Syndrome in pregnancy did not affect women's anxiety or concern about the health of their babies.⁴³

A minority of women still had some concern after undergoing the scan. This was independent of findings at scan, past obstetric history or information, interaction with staff. It may be an indication of trait anxiety in these women. Most of the women were happy with the scan and did not feel any more anxious after the scan.

Most of the women who had concerns for the baby's health also felt concern for their own health. Reasons for this concern included smoking, low lying placenta and other medical disorders. A study done by Homer⁴³ showed that underlying anxiety was similar in patients who had normal pregnancies and in those who "risk associated pregnancies."

Anxiety or worry is inevitably created in the small proportion of women who receive bad news but it is a trade-off between the large majority of women who are reassured and small number who have adverse outcomes, which are endemic to all screening tests²⁷.

Our study showed a significant decrease in concern for the baby's health after the scan. This may be attributed to seeing the baby, having the image explained and good communication with the ultrasonographer.

Most of the women thought that a normal fetal anomaly scan meant that everything was normal and that the pregnancy would continue without any problems. This is an unrealistic expectation as scans can only detect certain abnormalities, soft markers of genetic disorders and the scan cannot predict other obstetric complications including intrapartum problems. However, it may be that the experience of the scan was so overwhelming that remote possibilities of pregnancy complications seem improbable. It may, therefore, be argued that it is important to give detailed information about routine ultrasound scanning and additional tests that may be required be relayed to the woman prior to the examination as any misunderstandings of the capabilities and limitations of the examination can lead to expectations that may exceed that which the technology is capable of delivering.

In conclusion, ultrasound scanning has 3 main elements: meeting the baby, a visual confirmation of the reality of the pregnancy and reassurance about the well being of the fetus. All this make ultrasound an appealing screening tool to parents.¹¹ The benefits greatly outweigh any physical or emotional risks of routine ultrasound during pregnancy. It may be necessary to review the information given to women presenting for the scan and to improve the communication between the health care worker performing the scan and the women and her partner.

VALUE OF THIS STUDY

This is the first South African study to look at how women in our setting view the fetal anomaly scan. As most of the studies were from developed countries with comprehensive healthcare systems. Our women are a mix of both rural and urban people as well as refugees who access our obstetric services.

It seems obvious that information imparted by the correct medium, at the correct time may clear some of the misconceptions, further research is necessary regarding methods, amount and timing of this information. It is not clear what form this information should take.

Almost all our woman were happy with the service they get from the ultrasonographer.

Our study has shown that a 35% of our sample were no longer in a relationship so early into a pregnancy and women need to face this exciting but stressful period alone.

There is good correlation between the expectations and experiences. There are still women who do not book early enough to have a fetal anomaly scan and even if they do, the uptake for these scans are not close to 100% as it should be. This is because of inadequate resources and staff. This is currently being

addressed in the service. It is often taken for granted that women do want to go for an ultrasound scan to see or meet their baby.

University of Cape Town

LIMITATIONS

The study was not blinded therefore the ultrasonographers were aware that we were interviewing the patients. This may have influenced their interaction with the patients.

Women may be giving answers they think the investigator wants to know and may not be a true reflection of how they really feel.

We did not differentiate between intrauterine fetal deaths and neonatal deaths and did not ask where the loss occurred in relation to the obstetric history. It would've been interesting to stratify women according to income group and see whether there would be any impact on our findings by level of income.

It is interesting to note that a third of women who presented to the midtrimester scan was no longer in a relationship so there are other psychological stressors which these women have to deal with and this may overshadow the genuine feelings of hope or concern regarding the scan.

The provision of information is an integral part of better understanding of and expectation from the scan. We did not look at this in specific detail and it would be interesting to see how women would respond to these questions if they were adequately counselled about the ultrasound process which is the midtrimester fetal anomaly scan.

We may introduce a basic information leaflet for women to read prior to coming for the midtrimester scan. This, however, must be piloted as different studies have shown that too much information may be detrimental and women forget what they read if it is given too far in advance.

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APPENDIX 1

PATIENT CONSENT FORM

University of Cape Town

Department of Obstetrics and Gynaecology

**Informed consent for the
Patient Expectations and Experiences of Routine Scans (PEERS) Study**

Principal Investigator:

Dr Malika Patel

Study Title:

A prospective evaluation of the expectations and experiences of women having a routine ultrasound scan for fetal anomalies at 22 weeks of pregnancy

This Informed Consent Form has two parts:

- Information Sheet (to share information about the research with you)
- Certificate of Consent (for signatures if you agree to take part)

You will be given a copy of the full Informed Consent Form

PART 1: INFORMATION SHEET

Dr Patel is the main investigator in this project. She is training to be a specialist in Obstetrics and Gynaecology at the University of Cape Town and works at Mowbray Maternity, Groote Schuur and New Somerset Hospitals. She is doing research on ultrasound examinations during pregnancy.

This leaflet is designed to give you information about the research and invite you to be part of the study. You may want to think about it first and you are free to ask any questions about the study. If the form contains any words you don't understand, please ask her or any of the other researchers.

Lots of women have ultrasound scans during pregnancy. When women book early enough they can have a routine scan. We would like to find out what women expect when going for a routine scan. We would also like to find out what women feel about the scan once they have had it. This information will be helpful in deciding how to look after pregnant women in the future.

This research will involve you answering a few questions before and again immediately after the scan. One of the researchers will help you complete the form.

You are being invited to take part in this research because you have booked early enough to have a routine scan. We are interested to know your views about this scan.

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate all the services you receive at this hospital will continue and nothing will change.

We are asking you to help us learn more ultrasound scans during pregnancy and how you feel about the scans. We are inviting you to take part in this research project.

If you accept, you will be asked to:

- fill out a questionnaire before your scan;
- the questionnaire which will be provided by one of the researchers;
- the researcher will ask you the questions and fill out the form with you;
- you will then go for the scan; no changes have been made to the procedure of the scan;
- after the scan the same person will fill out the second questionnaire with you.

If you do not wish to answer any of the questions included in the questionnaire, you may skip them and move on to the next question.

The information recorded is confidential, and no one else except for Dr Patel and the researcher who interviewed you will have access to your answers. Your name will not be recorded on any of the documents.

There is a risk that you may share some personal or confidential information by chance, or that you may feel uncomfortable talking about some of the topics. However, we do not wish for this to happen. You do not have to answer any question or take part in the interview if you feel the question(s) are too personal or if talking about them makes you uncomfortable.

Your participation is likely to help us find out more about how to prepare women and doctors and nurses for scans in the future.

PATIENT CONSENT FORM

Maternal expectations and experiences of the routine second trimester ultrasound scan.

I, folder number

CONFIRM THAT:

I have been asked to participate in the above mentioned research project of the Department of Obstetrics and Gynaecology of the University of Cape Town.

The nature of the study has been discussed with me.

I have had the opportunity to ask questions about the study and any questions I have asked have been answered to my satisfaction.

I understand that:

- Participation will not result in any additional costs for me.
- All information gathered from the study is confidential.
- Participation in the study is voluntary and refusal to take part will in no way affect my care.
- I am free to withdraw from the study at any time.

I have read the foregoing information, or it has been read to me. I consent voluntarily to participate as a subject in this study and understand that I have the right to withdraw from the study at any time without it affecting my further medical care.

SIGNATURE :

DATE :

WITNESS :

APPENDIX 2
PRESCAN QUESTIONNAIRE

ULTRASOUND QUESTIONNAIRE

A. PRE-SCAN

STUDY NUMBER

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FOLDER NUMBER:

GSH		MMH		NSH	
------------	--	------------	--	------------	--

1. AGE:

2. RACE:

3. RELATIONSHIP:

1. Single	
2. Married	
3. Living with partner	
4. Other	

4. Level of education: (Tick one block please)

1. No formal education	
2. Schooling 1-7 years	
3. Schooling 8-11 years	
4. Matric or further studies	

5. Previous pregnancies

GRAVIDA	PARA		
Have you experienced any of the following?		YES	NO
1. Miscarriages or ectopic pregnancies			
2. Stillbirth or neonatal death			
3. One or more live children			

6. Please tell us whether this a planned pregnancy?

This pregnancy is:

1. Unplanned and not wanted	
2. Unplanned and wanted	

3. Planned but no longer wanted	
4. Planned and wanted	

7. Who is accompanying you to this scan?

YES

NO

0. Alone		
1. Husband or partner		
2. Mother		
3. Any other person		

8. Did you know that you could have someone accompanying you to the scan?

1. YES	
2. NO	

9. If you had a scan in a previous pregnancy, what was the reason?

0. No previous pregnancies	
1. Routine at 20-22 weeks	
2. Early pregnancy problems	
3. Diagnosis of pregnancy or to see how far you were pregnant	
4. Requested by patient	
5. No previous scans	
6. Other	

10. What do you expect from this scan?

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11. You have told me your expectations about the scan. I would like to ask you some specific questions about the scan which you may answer with 'YES', 'NO', or 'DO NOT KNOW'

Do you expect the scan to tell you any of the following?

YES NO DON'T

KNOW

1. That the baby is alive?			
2. That the baby is normal			
3. That there is more than 1 baby			
4. How far pregnant you are			
5. The sex of the baby			

12. From whom or from where did you receive information regarding this scan. Please answer YES or NO. You may give more than one answer.

YES NO

0. I was given no information		
1. Family and friends		
2. Nurse or doctor		
3. Pamphlet/poster in the clinic		
4. Information outside of the clinic		

13. Were you given the choice of whether to have the scan or not?

1. YES	
2. NO	

14. Can you please describe in your own words your feelings about having this scan?

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15. Do you have concerns about having this scan?

1.YES	
2.NO	

16. If the answer to Question 15 in 'NO', do not ask any further questions. If the answer is 'YES', please continue with the following questions:

You have indicated that you have concerns about having this scan. Please explain in your own words what these concerns are:

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17. In addition to the concerns raised in the previous question, please indicate if any of the following do concern you. Please answer 'YES' or 'NO'

	YES	NO
1. Are you concerned about the baby's health		
2. Are you concerned about your own health		
3. Are you concerned the scan may be dangerous to you		
4. Are you concerned the scan may be dangerous to baby		

18. If you answered 'YES' to any of the above, please tell us how concerned you are about anything in question 17 use the scale of 1-5 where 1 is not concerned at all and 5 is very concerned or distressed.

17.1 Concerned about the baby's health

1	2	3	4	5
SLIGHTLY CONCERNED				VERY CONCERNED

17.2 Concerned about your own health

1	2	3	4	5
SLIGHTLY CONCERNED				VERY CONCERNED

17.3 Concerned that the scan may be dangerous to you

1	2	3	4	5
SLIGHTLY CONCERNED				VERY CONCERNED

17.4 Concerned that the scan may be dangerous to baby

1	2	3	4	5
SLIGHTLY CONCERNED				VERY CONCERNED

University of Cape Town

APPENDIX 3

POSTSCAN QUESTIONNAIRE

University of Cape Town

B. POST-SCAN**STUDY NUMBER**

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FOLDER NUMBER:

1. Did you see or were you told any of the following during the scan?

	YES	NO	UNSURE
1. That the baby is alive?			
2. If the baby is normal			
3. If there is more than 1 baby			
4. How far the pregnancy is			
5. The sex of the baby			

2. Now that you have had the scan, how helpful was the information you received. Please indicate below your opinion of the information you received

0. No information	
1. Not helpful	
2. A bit helpful	
3. Very helpful	

3. If the information was less than helpful, tell us what would have prepared you better?

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4. Now that you have had the scan, would you have liked to have been given a choice to have the scan

0. I was given a choice	
1. No, I would have wanted the scan anyway	
2. Yes, but I would have had the scan anyway	
3. Yes, and I would have thought about it	
4. Yes, and I may not have had the scan	

5. Was there anything you disliked about the scan? If so, please tell me what you did not like about the scan

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6. Now that you have had the scan, please tell me what was the best part was about having the scan.

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7. Then ask: I would like to ascertain whether any of the following concerned you. Please answer 'YES' or 'NO'

	YES	NO
1. The uncertainty		
2. The dark room		
3. The cold gel		
4. No explanation during scan		
5. Lack of communication		
6. Other		

8. Then ask: I would like to ascertain whether you were excited about any of the following. Please answer 'YES' or 'NO'

YES NO

1. Seeing the baby		
2. Hearing the heart beating		
3. Being told baby is healthy		
4. Sharing the moment with my partner		
5. Having my questions answered		

9. Now that you have had the scan what are your feelings? You may select more than one of the options below:

0. No specific feelings	
1. Concerned about the baby's health	
2. Concerned about my health	
3. Concerned that the scan is dangerous for me	
4. Concerned that the scan is dangerous for baby	
4. Happy	
5. Excited	
6. The pregnancy feels real now	

10. If you had no concerns, please move on to Question 11. If you had certain concerns raised in question 9, please tell me how concerned you were. Please use the scale of 1-5 where 1 is not concerned at all and 5 is very concerned.

10.1 Concerns about the baby's health

1	2	3	4	5
SLIGHTLY CONCERNED				VERY CONCERNED

10.2 Concerns about your own health

1	2	3	4	5
SLIGHTLY CONCERNED				VERY CONCERNED

10.3 Concerns that the scan may be dangerous for me

1	2	3	4	5
SLIGHTLY CONCERNED				VERY CONCERNED

10.4 Concerns that the scan may be dangerous for the baby

1	2	3	4	5
SLIGHTLY CONCERNED				VERY CONCERNED

11. Are there any comments you have on the experience?

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12. What does a normal scan mean to you?

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APPENDIX 4

ETHICS APPROVAL

APPENDIX 5
DATA SPREADSHEET-sample

University of Cape Town

												Pregnancy
												1=unplanned unwanted
												2=unplanned wanted
												3=planned not wanted
												4=planned and wanted
Study Number	Folder Number	Site: 1=GSH 2=MMH 3=NSH	Age	Race: 1=Black 2=Coloured 3=White 4=Unknown	Relationship 1=Single 2=Married 3=Partner 4=Other	Education 1=None 2=1-7 Years 3=8-11 4=Matric+	Gravida	Para	Misc or ectopic 0=No 1=Yes	SB or NND 0=No 1=Yes	1 or more live children 0=No 1=Yes	
1	23787088	3	30	1	2	4	1	0	0	0	0	4
2	23810500	3	27	1	2	4	1	0	0	0	0	4
3	23844079	3	26	1	3	4	2	1	0	0	1	4
4	20706156	3	20	2	4	4	1	0	0	0	0	4
5	23849581	3	24	2	2	3	2	1	0	1	0	2
6	23875636	3	34	1	2	3	4	3	0	1	1	4
7	23855729	3	24	1	1	4	1	0	0	0	0	2
8	23498629	3	24	1	1	3	2	1	1	0	0	4

Accompanied 0=None 1=Husband/partner 2=Mother 3=Other 4=2 or more people	Knew could be accompanied 1=Yes 2=No	Previous pregnancy scan	0=None or 1=Routine scan	0=None or 1=Baby alive	0=None or 1=Baby healthy	Expect scan to tell baby alive	Expect scan to tell baby is normal	Expect scan to tell more than 1 baby	Expect scan to tell how far pregnant	Expect scan to tell sex of baby	Given no information 1=Yes 2=No	Information from family and friends 1=Yes 2=No
		0=None or 1=Baby alive	0=None or 1=Baby healthy	0=None or 1=Gestation on	0=None or 1=Gestation on							
0	1	0	2	7	7	1	1	1	3	1	2	2
1	1	0	1	7	7	3	1	1	3	1	2	2
0	2	5	0	7	7	3	1	3	3	3	1	2
1	1	0	2	7	7	1	1	2	1	1	2	1
1	1	4	6	7	7	1	1	1	1	1	2	2
1	1	4	4	7	7	1	1	1	1	1	2	1
0	1	0	4	7	7	1	1	1	1	1	2	2
0	2	2	4	7	7	3	1	1	1	1	2	2

Information from nurse or doctor	Information from poster in clinic	Information from outside clinic	Choice to have scan	Feelings about scan:	Concerns	Unprompted concerns	Prompted concerns: Baby's health	Prompted concerns: Own health	Prompted concerns: Scan dangerous to mom	Prompted concerns: Scan dangerous to baby	Level of concern re baby's health	Level of concern re own health
1=Yes 2=No	1=Yes 2=No	1=Yes 2=No	1=Yes 2=No	0=None 1=Good 2=Excited 3=Concerned 4=Afraid 5=Other	1=Yes 2=No	0=None 1=Baby's health 2=Own health 3=Scan dangerous to mom 4=Scan dangerous to baby 5=Multiple pregnancy 6=Other	0=N/A 1=Yes 2=No	0=N/A 1=Yes 2=No	0=N/A 1=Yes 2=No	0=N/A 1=Yes 2=No	0=N/A 1=vslight 2=Slight 3=Average 4=Moderate 5=Very	0=N/A 1=vslight 2=Slight 3=Average 4=Moderate 5=Very
2	2	1	2	1	2	0	0	0	0	0	0	0
1	2	2	1	2	1	6	1	1	2	2	5	3
2	2	2	2	3	1	6	1	1	2	2	3	3
1	2	2	2	2	1	1	1	1	2	2	5	5
1	2	2	2	2	2	0	0	0	0	0	0	0
2	2	2	2	2	2	0	0	0	0	0	0	0
1	2	2	2	2	2	0	0	0	0	0	0	0
1	2	2	2	2	2	0	0	0	0	0	0	0

Level of concern re danger to mom 0=N/A 1=vslight 2=Slight 3=Average 4=Moderate 5=Very	Level of concern re danger to baby 0=N/A 1=vslight 2=Slight 3=Average 4=Moderate 5=Very	Did you see or were told the baby is alive 1=Yes 2=No 3=Unsure	Did you see or were told the baby is normal 1=Yes 2=No 3=Unsure	Did you see or were told there is 1 baby 1=Yes 2=No 3=Unsure	Did you see or were told how far the pregnancy is 1=Yes 2=No 3=Unsure	Did you see or were told the sex of the baby 1=Yes 2=No 3=Unsure	Information received 0=None 1=Not helpful 2=A bit helpful 3=Very helpful	Better information 0=None 1=Nurse or doctor 2=Pamphlet 3=Video 4=Talking to other patients 5=Other 6=Don't know	Choice given 0=Was 1=No 2=Yes but wanted 3=Yes 4=Yes 5=Other 6=Don't scan	Dislikes: 0=None 1=Dark room 2=Cold gel 3=No communication 4=Too quick 5=Could not see clearly 6=No picture 7=Questions not answered 8=Other	Best part: 0=None 1=See baby 2=See heart beat 3=See sex 4=Healthy baby 5=Only one baby 6=Other	Prompted concerns: Uncertainty 1=Yes 2=No
0	0	1	1	2	1	1	3	0	2	7	4	2
1	1	1	1	2	1	1	2	6	1	0	4	2
1	1	1	1	2	1	1	0	0	1	0	1	1
1	1	1	1	1	1	1	3	0	1	0	2	1
0	0	1	1	1	1	1	3	0	2	0	1	1
0	0	1	1	2	1	1	2	5	2	0	3	2
0	0	1	1	2	1	2	2	0	2	0	1	2
0	0	1	1	2	1	1	3	0	1	0	3	1

Prompted concerns: Dark room	Prompted concerns: Cold gel	Prompted concerns: No explanation	Prompted concerns: No communication	Prompted concerns: Other	Excited about: Seeing the baby	Excited about: Hearing the heart beating	Excited about: Told baby is healthy	Excited about: Sharing with partner	Excited about: Questions answered	Feelings after scan: None specific	Feelings after scan: Concern about baby's health	Feelings after scan: Concern about mom's health
1=Yes 2=No	1=Yes 2=No	1=Yes 2=No	1=Yes 2=No	1=Yes 2=No	1=Yes 2=No	1=Yes 2=No	1=Yes 2=No	1=Yes 2=No	1=Yes 2=No	0=N/A 1=Yes 2=No	0=N/A 1=Yes	0=N/A 1=Yes
2	1	2	2	1	1	1	1	0	1	0	0	0
2	1	2	2	2	1	1	1	1	1	0	0	0
1	1	2	2	2	1	1	1	0	0	0	0	0
2	2	2	2	2	1	1	1	1	1	0	0	0
2	2	2	2	2	1	1	1	1	1	0	0	0
2	2	2	2	2	1	1	1	0	0	0	0	0
2	2	2	2	2	1	1	1	0	1	0	0	0
2	2	2	2	2	1	1	1	0	1	0	0	0

Feelings after scan:	Feelings after scan:			Feelings after scan:	Level of concern re baby's health 0=N/A 1=vslight 2=Slight 3=Averag e 4=Modera te 5=Very	Level of concern re own health 0=N/A 1=vslight 2=Slight 3=Averag e 4=Modera te 5=Very	Level of concern re danger to mom 0=N/A 1=vslight 2=Slight 3=Averag e 4=Modera te 5=Very	Level of concern re danger to baby 0=N/A 1=vslight2 =Slight 3=Averag e 4=Modera te 5=Very
Concern scan dangerou s for mom 0=N/A 1=Yes	Concern scan dangerou s for baby 0=N/A 1=Yes	Feelings after scan: Happy 0=N/A 1=Yes	Feelings after scan: Excited 0=N/A 1=Yes	Pregnanc y feels real now 0=N/A 1=Yes				
0	0	1	0	0	0	0	0	0
0	0	1	0	0	0	0	0	0
0	0	1	0	0	0	0	0	0
0	0	1	1	0	0	0	0	0
0	0	1	0	0	0	0	0	0
0	0	1	0	0	0	0	0	0
0	0	1	0	0	0	0	0	0
0	0	1	0	0	0	0	0	0